



Enduring Questions on Disability

On behalf of the Disability
Data and Evidence Working Group

28 October 2016



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Contact: Evidence_Working_Group@msd.govt.nz

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Introduction

In the 2013 Disability Survey¹, 24 percent of the New Zealand population was estimated to be disabled; a total of 1.1 million people. Currently, there is no shared understanding of the data and evidence needs relating to disabled people in New Zealand.

To help build this understanding, the following questions need to be answered:

- What data and evidence about the lives of disabled people are needed to inform policy, plan services, and monitor progress?
- What are the least intrusive, and most cost effective, ways to ensure that the relevant information is available when required?

It is against this background that the Disability Data and Evidence Working Group (DDEWG) was established in 2015.

The DDEWG is jointly facilitated by the Office for Disability Issues and Statistics New Zealand and has representatives from government agencies, Disabled People's Organisations, service providers, and academic institutions.² The DDEWG aims to define, clarify and prioritise disability information needs and to recommend strategies to address information gaps.

To achieve its aims the DDEWG has been developing a Disability Data and Evidence Plan.

Disability Data and Evidence Plan

The purpose of the Disability Data and Evidence Plan (DDEP) is, firstly, to develop a shared understanding of the strengths, gaps, overlaps and deficiencies in available data and evidence relating to disabled people. Identified inadequacies in the available data and evidence will then be prioritised and strategies developed to address them. Carrying out recommended strategies will be funding-dependent.

The end-goal is to improve the availability of important information for policy and funding decisions that affect the lives of disabled people. In addition, monitoring key aspects of disabled peoples' lives compared with others helps to ensure that the rights of all people are being upheld.

The development of the DDEP is being carried out in four stages. These are:

1. Develop an agreed set of enduring questions (on-going data needs).
2. Carry out stocktakes³ of the data and evidence currently available.
3. Analyse the stocktakes and data needs to identify gaps in available information.
4. Prioritise gaps in available information and develop strategies to address them.

What are enduring questions?

'Enduring questions' are the way in which on-going data and evidence needs are represented in the DDEP. They are open-ended questions organised under a series of

¹ http://www.stats.govt.nz/browse_for_stats/health/disabilities/DisabilitySurvey_HOTP2013.aspx

² The members of the DDEWG at 28 September 2016 are listed in Appendix 1.

³ <http://www.odj.govt.nz/what-we-do/better-evidence/index.html>

topics. Enduring questions focus on aspects of each topic that are likely to remain of interest or concern for the foreseeable future and that can be regularly updated and compared over time. The questions should be interpreted broadly, they are a starting point for discussion about the types of evidence that are useful to inform decision-making and monitor progress.

How were the enduring questions developed?

At a workshop attended by members of the DDEWG in May 2016, a brain-storming session resulted in a wide range of topics under which enduring questions could be developed. Statistics New Zealand collated and analysed the suggested topics and drafted lists of enduring questions under each. Members of the DDEWG then provided feedback.

In August 2016, a public consultation on the draft enduring questions took place. Three workshops were held. Participants, with an interest in information and research about disabled people, came from across New Zealand. These stakeholders included: government agencies, independent organisations, Disabled People's Organisations, the [New Zealand Disability Strategy Revision Reference Group](#), service providers and universities/research institutes.

In August/September 2016 the Office for Disability Issues hosted an online public consultation on its website.

The end-result of these consultations was a set of topics and questions ranging from the labour market to health to personal safety and civil protection. In this document each topic is introduced with a brief description and the related enduring questions are listed.

How will the enduring questions be used?

Stocktakes of currently available data and evidence have been carried out. A gap analysis will be used to see how well available information sources can meet the information needs identified in the enduring questions.

The final stage of the DDEP will be the development of a prioritised list of targeted initiatives to address gaps or deficiencies in available information. The process will be informed by the current [revision of the New Zealand Disability Strategy](#) and the development of an outcomes framework for the new strategy.

The Disability Data and Evidence Plan will provide a shared and up-to-date understanding of the data and evidence required to support sound policy and appropriate services to meet the needs of disabled New Zealanders. Recommendations on how priority data needs could be addressed will be made and knowledge and understanding about disability issues will be improved across the wider disability sector in New Zealand.

Note on terminology for comparisons

The enduring questions wording use the term "others" to cover all population groups with which data about disabled people might be compared. This terminology aligns with that of the UN Convention on the Rights of People with Disabilities (UNCRPD) and does not preclude comparisons between different groups of disabled people or with the total population.

The International Classification of Functioning, Disability and Health

The DDEWG recognised the need for a shared understanding of disability to underpin the development of the Disability Data and Evidence Plan. After exploration and discussion of options the DDEWG is using the International Classification of Functioning, Disability and Health, commonly referred to as the ICF, as the conceptual base for the Disability Data and Evidence Plan.

What is the ICF?

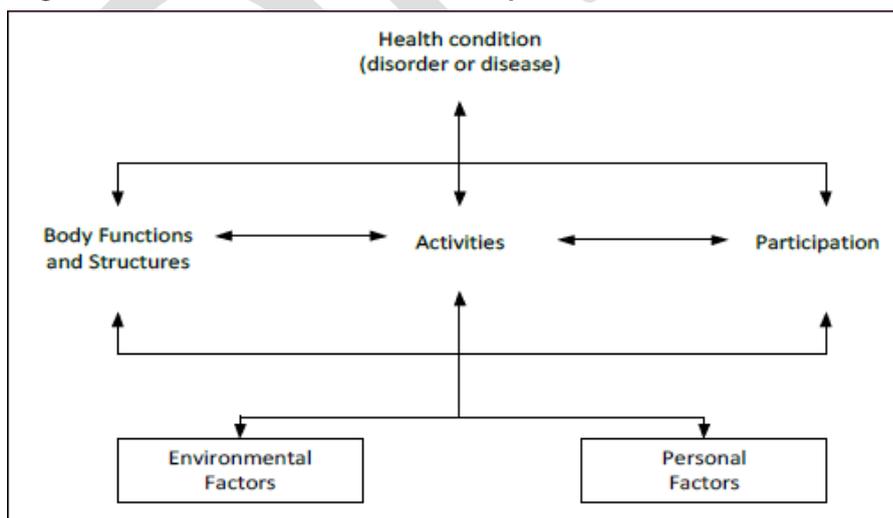
“The International Classification of Functioning, Disability and Health (ICF) is a framework for describing and organising information on functioning and disability. It provides a standard language and a conceptual basis for the definition and measurement of health and disability.

The ICF was approved for use by the World Health Assembly in 2001, after extensive testing across the world involving people with disabilities and people from a range of relevant disciplines. A companion classification for children and youth (ICF-CY) was published in 2007.

The ICF integrates the major models of disability. It recognises the role of environmental factors in the creation of disability, as well as the relevance of associated health conditions and their effects.”⁴

As the diagram below shows, the ICF presents an understanding of disability as a multi-dimensional experience resulting from the interaction between people’s health condition(s), environmental factors and personal factors (Figure 1).⁵ The ICF is referred to as a biopsychosocial model of disability, as it synthesises elements of the medical and social models of disability.

Figure 1: Interaction between the components of the ICF



⁴ The ICF: An Overview. https://www.cdc.gov/nchs/data/icd/icfoverview_finalforwho10sept.pdf

⁵ World Health Organisation. (2002) *Towards a Common Language for Functioning, Disability and Health*. Geneva, page 9

Why use the ICF?

The ICF is applicable to all people, irrespective of their physical, social and cultural contexts. The ICF:

- provides a common language for discussing disability
- concepts and ethical principles align with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)
- underpins consistent data across time and place
- enables data comparisons and aggregations
- provides a consistent understanding across professional services, and with the people concerned
- provides for a wide range of uses in different sectors (such as education, health, transport)
- uses neutral language to record both positive and negative aspects of functioning and disability

Using the ICF

As shown in Figure 1, the ICF is an integrated, dynamic framework and as such, any claim to use of it should involve the adoption of all aspects of the model. To focus, for example, on personal factors (e.g. behavioural patterns), while ignoring the role of environmental factors in exploring how an individual functions in their society, would not be described as a valid use of the ICF model.

In addition, the ICF will not be appropriate for all disability research purposes. Understanding disability from a self-identity perspective is of on-going interest but this concept is not represented in the ICF. The DDEWG's use of the ICF does not preclude agencies and researchers from developing or using other conceptual frameworks for generating disability data and evidence.

Cross-cutting and Core Topics

A cross-cutting topic is one that is of interest in its own right and also one by which questions in other topics will need to be broken-down. Topics that are not cross-cutting are referred to as 'core'. There are 16 core topics.

This distinction aims to clarify that data collected in core topics will need to be broken-down by a range of personal and disability characteristics.

The first two topics in this document are cross-cutting:

- A. Disability, Impairments and Limitations
- B. Personal Characteristics

For example, the labour market questions in core topic one should be able to be broken-down by the cross-cutting topics. Each question can then be reported by characteristics such as disability status, impairment and limitation types and by personal characteristics, such as, age, sex, and ethnicity.

Three of the core topics are relevant across all aspects of people's lives. They are:

- Accessibility
- Attitudes and awareness
- Personal autonomy

These topics stand alone and are also relevant under each of the other core topics. Accessibility and attitudes/awareness are covered in the enduring questions on 'barriers and facilitators' while personal autonomy is made explicit under each topic in its own question.

Topic A: Disability, Impairments and Limitations

A person's impairments and limitations are unique and can affect them in different ways. The ICF describes impairment as a problem in body function or structure such as a significant deviation or loss. An individual's body functions and structures, interacting with environmental factors and personal factors, can result in activity limitations and participation restrictions.⁶

In official data collections it is functional or structural impairments and limitation in everyday activities that provide thresholds for eligibility (in administrative datasets) or for being counted as disabled (in population surveys). Eligibility for targeted services requires that applicants have, for example, a vision impairment or mobility limitations at some predetermined and measurable level. Combinations of impairment types and activity limitations at specified levels are used to set thresholds for who counts as disabled in population surveys or in data collections that are not specifically about disability support.

The extent of impairment or level of limitation a person has are also used in defining thresholds for the disabled population and understanding people's needs. The cause, duration and time of onset of impairments and limitations are important factors in understanding the effects of disability on people's lives.

The purpose of data collections will inform how thresholds of disability status are defined and which groups of disabled people are relevant.

Enduring questions on disability, impairment and limitations

1. What groups of disabled people are of interest (for policy and funding decisions, research, and monitoring systems) and why?
2. How are the groups of interest to be identified?
3. What types of impairments and limitations do disabled people have?
4. To what extent are people impaired or limited?
5. What are the causes of impairments and limitations?
6. At what ages do impairments and limitations start?
7. What is the duration of impairments and limitations?
8. How many impairments and limitations do disabled people have?
9. What underlying health conditions are associated with impairments or limitations (where relevant)?

⁶ <http://www.who.int/entity/classifications/icf/icfbeginnersguide.pdf?ua=1>

Topic B: Personal Characteristics

Demographic characteristics are fundamental to understanding any population group. They include the age profile, sex breakdown and the ethnic group distribution of the population of interest.

Other personal characteristics that are important in understanding disability in New Zealand were identified during consultation on this document. They include, geographic location, family-type, socio-economic and citizenship/residency status.

Answering the enduring questions on personal characteristics will allow us to quantify and describe aspects of the disabled population, and assess the situation of specified population subgroups (such as older people, women⁷ and children⁸) as required by the UNCRPD.

In all of the questions below we must be able to compare characteristics of the disabled population with those of the total population and the non-disabled population.

Enduring questions on personal characteristics

1. What is the age-structure of the disabled population and how does it compare with others?
2. What are the sex and gender distributions of the disabled population and how do they compare with others?
3. What is the ethnic-group distribution of disabled people and how does it compare with others?
4. Where do disabled people live⁹ and how does this compare with others?
5. With whom do disabled people live and how does this compare with others¹⁰?
6. What is the socio-economic status of disabled people¹¹ and how does it compare with others?
7. What is the citizenship / residency / migrant status of disabled people and how does it compare with others?

⁷ UNCRPD Article 6

⁸ UNCRPD Article 7

⁹ Geographic location to local authority level is needed

¹⁰ Includes household composition, relationship of household members, household and family size, number of dependent children etc.

¹¹ Includes the families and households of disabled people

Topic 1: Labour Market

Work provides people with opportunities to learn new skills and build social contacts as well as being the principal source of personal income. The UNCRPD requires that ratifying governments must 'recognize the rights of persons with disabilities to work on an equal basis with others', and outlines a number of steps to achieve this objective.¹²

Patterns of labour force participation cover a wide range of characteristics relating to the interaction between people and work. These include: labour force status¹³, employment status¹⁴ as well as length of employment, occupation, industry, and hours worked for those in employment. Labour underutilisation¹⁵ and levels of satisfaction with one's work are also important given different levels of need and desire to be employed.

Barriers to labour force participation may be physical, technological or attitudinal. Some global businesses view having accessible workplaces and employment circumstances as a competitive edge, and incorporate accessibility into their organisational culture.¹⁶

Article 27 of the UNCRPD requires that disabled people have 'the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible'.¹⁷ Understanding and influencing employers' views on engaging disabled people in their businesses is an important factor in ensuring greater access for all.

Enduring questions on the labour market

1. Do patterns of labour force participation differ between disabled people and others?¹⁸ If so, how?
2. What barriers and facilitators affect equitable employment outcomes for disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
3. How satisfied are disabled people with their labour force situation and how does this compare with others?
4. How well do current employment services¹⁹, systems²⁰ and policies²¹ meet the needs of disabled people?
5. How well do current employment services, systems and policies meet the needs of employers and potential employers of disabled people?

¹² United Nations [Convention on the Rights of Persons with Disabilities](#).

¹³ Employed, unemployed or not in the labour force

¹⁴ Wage or salary earner, employer, self-employed or unpaid relative assisting.

¹⁵ Underutilisation is a measure of labour market performance that includes underemployment, unemployment unavailable jobseekers and available potential jobseekers.

¹⁶ Global Reporting Initiative. (2015) *Disability in Sustainability Reporting* Available from [Disability in Sustainability Reporting](#). www.globalreporting.org

¹⁷ United Nations [Convention on the Rights of Persons with Disabilities](#)

¹⁸ Labour force patterns include labour force status, employment status, occupation and labour force attachment over time.

¹⁹ Services provide benefits that aim to meet people's needs. They can be public, private or voluntary, and operate at local, community, regional, or international level. People, associations, organisations, agencies or governments may provide them. The benefits provided by services can be general or specially designed.

²⁰ Systems relate to the administrative control and organisation of services by governments at local, regional, national, and international levels. Systems are designed to organise, control and monitor services that provide benefits to people.

²¹ Policies are rules, regulations, conventions and standards established by governments at the local, regional, national, and international levels, or by other recognised authorities. Policies govern and regulate the systems that organise, control and monitor services.

6. To what extent do disabled people have control over their labour market opportunities compared with others?

Topic 2: Education and Training

Access to quality education and training at all levels is an important determinant of life outcomes. Education enhances personal skills and knowledge, prepares individuals for the workforce, and improves life-satisfaction and social networks. There is an enduring need for information on participation and achievement in education and training to indicate how well New Zealand's systems and practices are working for disabled people.

Under Article 24 of the UNCRPD, access to free education at primary and secondary level in one's own community, with appropriate individualised support and reasonable accommodation,²² is the expectation. In New Zealand accessible pre-school education is also an essential requirement.

Systems and policies set the context within which people are educated and trained in New Zealand. We need to ensure that they are consistent with an inclusive view and designed to optimise outcomes for all in a non-disabling society. Transitions across level and type of education and from education to work are important life-stages at which personalised support needs to be in place.

An understanding of education and training achievement and participation by disabled people broken down by personal characteristics is required. It is important that we can look at differences, for example, by age-group and sex as well as by disability characteristics.

Enduring questions on education and training

1. Does participation in education²³ and training²⁴ differ between disabled people and others? If so, how?
2. Do levels of achievement in education and training differ between disabled people and others? If so, how?
3. What barriers and facilitators affect participation in education and training by disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
4. To what extent do disabled people have control over their education and training opportunities compared with others?
5. How well do current education and training services, systems²⁵ and policies meet the needs of disabled people?

²² Reasonable accommodation is: 'Necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms' (Article 2 of UN [Convention on the Rights of Persons with Disabilities](#).)

²³ Includes by level: pre-school / primary / intermediate / secondary / tertiary as well as by distinctions such as special schools / mainstream schools; private / state funded; residential / day-school.

²⁴ Includes apprenticeships, trade courses, and training establishments.

²⁵ Including the training of education and training professionals.

Topic 3: Health

Achieving a high level of positive health outcomes across the population is fundamental to a non-disabling society. In order to understand health outcomes, we must understand the determinants of health status and the barriers that people face in attaining good health. Self-assessed health and medically-assessed health status are both important indicators of morbidity. Any differences in life expectancy and death rates also need to be examined. Where disparities in health status exist, we need to understand what is causing them.

Analysis of the relationship between health outcomes and personal characteristics helps us to understand how a range of factors can affect health. Data should be available in a format that allows for this type of analysis as well as analysis by disability characteristics.

Health services must be accessible to all and provided in a way that addresses both diversity and personal dignity. Recognising that disabled people have the right to enjoy the highest standard of attainable health without discrimination is a requirement under Article 25 of the UNCRPD²⁶.

Given developments in bioethical research and advances in bio-technology, the relationship between pre-natal diagnosis and outcomes is becoming a significant concern for many people. It is important to treat issues of bio-ethics and bodily integrity with sensitivity, giving due regard to disabled people's rights and their informed consent.

Enduring questions on health

1. Does the health status of disabled people differ from that of others? And if so, how?
2. Does life expectancy differ between disabled people and others? If so, how?
3. Do mortality rates and causes differ between disabled people and others? If so, how?
4. What barriers and facilitators affect the health status of disabled people (including, amongst other things, attitudes and awareness²⁷, health literacy and accessibility²⁸)?
5. To what extent do disabled people have control over their use of health services and products compared with others?
6. How well do current health products and services²⁹, systems³⁰, and policies³¹ meet the needs of disabled people?

²⁶ United Nations [Convention on the Rights of Persons with Disabilities](#).

²⁷ Including dignity and respect.

²⁸ Including funding difference of ACC vs non-ACC cases.

²⁹ Including rehabilitation services, health promotion and disease prevention programmes.

³⁰ Including the training of health professionals.

³¹ Including current understandings and practices associated with bioethical issues.

Topic 4: Domestic Accommodation

A place to live is a basic need. Our homes provide shelter, security, privacy, and personal space and are also important places for fostering and maintaining relationships. The type and quality of a person's home has major implications for their health and well-being.³²

Living independently is not just about where you live but also with whom you live and whether the residence is suitable for your needs. Having the ability to choose their place of residence and with whom they live is a right for all people and is specified in Article 19 of the UNCRPD.³³

Housing quality includes physical aspects of the building, both interior and exterior, as well as living conditions such as dampness, the ability to heat rooms, and the provision of functioning utilities like water, sewerage and power.

Housing quality is also about the suitability of the home for the people who live there – in terms of the size, the facilities available and affordability. Where guidelines and regulations exist to support housing quality, we need to understand the extent to which these obligations are being met.

Enduring questions on domestic accommodation

1. In what types of private and non-private dwellings do disabled people live and does this differ from the living arrangements of others?³⁴
2. Does the quality of domestic accommodation differ between disabled people and others?
3. Does the domestic accommodation in which disabled people live meet their needs?³⁵
4. What barriers and facilitators³⁶ affect the ability of disabled people to live in domestic arrangements that meet their needs (including, amongst other things, attitudes and awareness, and accessibility)?
5. To what extent do disabled people have control over where and with whom they live compared to others?
6. How well do current housing products and services, systems and policies meet the needs of disabled people?

³² Statistics New Zealand (2015) Measuring housing quality: *Potential ways to improve data collection on housing quality in New Zealand*. Available from stats.govt.nz [Measuring housing quality](#)

³³ United Nations [Convention on the Rights of Persons with Disabilities](#).

³⁴ Includes dwelling-type and tenure (ownership of dwelling). Dwelling type covers private housing, social housing, community housing and institutional housing (prisons, hospitals, residential care facilities).

³⁵ Includes access to affordable home ownership as well as the physical aspects of the home.

³⁶ Such as universal design

Topic 5: Travel

The ability to travel, including local, national and international journeys, is a fundamental part of modern life and, for most, local trips are an everyday activity. When travel is difficult, or impossible, participation in a wide range of activities will be affected. This is not merely inconvenient; it can lead to social isolation, loneliness and poor health.³⁷

Accessible transport is important for ensuring equality of opportunity for all people. The mode (type of transport), time taken (wait time and length of journey) and cost are all important aspects of a journey. Getting to and from transport facilities must also be considered.

Disabled people face a range of environmental barriers in both short and long-distance travel. For a pedestrian the quality of footpaths, including the gradient and condition of the surface and access to safe road crossings, can significantly affect a journey. Trained transport staff, kneel-buses, and accessible information about transport services³⁸ will make public transport more accessible for all people.

Private transport is a major form of travel in New Zealand and driving or travelling as a passenger may be made possible if private vehicles are modified. We need to understand the extent to which people are able to access modifications that allow them to use private transport and what barriers might prevent this.

The accessibility of all forms of transport and barriers faced, including for disabled people, is included in the enduring questions for the Transport Domain Plan published in January 2015 by Statistics New Zealand and the Ministry of Transport.³⁹

Enduring questions on travel

1. Do patterns of short and long distance travel differ between disabled people and others? If so, how?
2. What barriers and facilitators affect the achievement of equitable access to local places for disabled people (including, amongst other things, attitudes and awareness, cost and accessibility)?
3. What barriers and facilitators affect the achievement of equitable access to national and international places for disabled people (including, amongst other things, attitudes and awareness, cost and accessibility)?
4. To what extent do disabled people have control over their travel options compared with others?
5. How well do current transport services, systems and policies meet the needs of disabled people?

³⁷ Hine, Julian. Mitchell, Fiona. (2001) *Better for Everyone? Travel Experiences and Transport Exclusion*. Urban Studies (Routledge), 01/02/2001, Vol. 38 Issue 2, p319-332, 14p.

<http://www.barrierfreenz.org.nz/technical/accessibility-principles.html>

³⁸ Waikato Regional Council. (2015) [Measuring Accessible Journeys](#)

³⁹ <http://www.transport.govt.nz/research/transport-domain-plan>

Topic 6: Standard of Living

A person's standard of living includes the level of comfort, material goods and necessities available to them. Standard of living can differ by location and across a person's lifetime. In a market economy standard of living is almost entirely dependent on the monetary income that can be accessed either by the person themselves or through the activities and entitlements of members of their family or household. The incomes of extended family and friends or inherited and accumulated wealth can also influence living standards.

With higher levels of income and wealth a person, family or household will be more resilient to shocks to employment or health, or from the effects of a natural disaster. People with higher incomes are able to access safer, healthier and more suitable homes and create more comfortable and desirable living conditions. They are also able to put aside income for retirement. When people are unable to access sufficient income or reserves to provide a minimal standard of living for themselves and their dependents, life chances and outcomes will be reduced.

The amount of free time available for rest and recreation is an important aspect of personal well-being, and is one measure of the standard of living of a given population. Time use information is used to measure differences in the time committed to paid work, household work and free time as a measure of comparative living standards.⁴⁰

Enduring questions on standard of living

1. Do levels of income (personal and household) differ between disabled people and others? If so, how?
2. Do levels of wealth (personal and household) differ between disabled people and others? If so, how?
3. Do levels of material standard of living differ between disabled people and others? If so, how?
4. Do disabled people acquire sufficient income to meet their needs, including the need to save for the future? If so, how?
5. What barriers and facilitators influence the achievement of equitable living standards by disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
6. How well do current systems and policies for income support meet the needs of disabled people?
7. What is the financial cost of disability to disabled people and their families?
8. Do patterns of time-use differ between disabled people and others? If so, how?

⁴⁰ Fleming R and Spellerberg A (1999). Using time use data: A history of time use surveys and uses of time use data, Statistics New Zealand, Wellington.

Topic 7: Support Services

Access to a range of support services, including both formal and informal networks, is essential to personal well-being. Formal systems of social support include services that are provided by central and local government, and by community agencies, both commercial and non-for-profit. It is important to understand the uptake of both disability-specific and mainstream social support services.

As with all services, barriers to accessing support can include the built environment, the attitudes and awareness of people providing services, the availability of suitable products and technologies, and the legislative and regulatory frameworks within which service systems are embedded.

In addition to formal services people are supported by family and friends. The extent to which these informal networks are able to provide people with support that they need during different phases of their lives is an important determinant of life quality. It is also important to ensure that people who are supporting disabled people are themselves supported in this role⁴¹.

Enduring questions on support services

1. How do patterns of social service use differ between disabled people and others?
2. What barriers and facilitators influence the use of support services by disabled people (including, amongst other things, attitudes and awareness, cost and accessibility)?
3. How well do current support services, systems and policies meet the needs of disabled people⁴²?
4. To what extent do disabled people have control over their use of support services compared with others?
5. To what extent do disabled people use informal support networks compared with formal support services and why?
6. How well supported are people who provide support for disabled people?

⁴¹ See <https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/> for information on the New Zealand Carers' Strategy.

⁴² Includes habilitation services.

Topic 8: Community and Social Life

Community groups, both formal and informal, provide opportunities to engage with people who share interests and beliefs. Service and religious organisations, local social clubs and professional associations are examples. Article 19 of the UNCRPD requires that disabled people have the same right as others to full inclusion and participation in the community.

Informal social networks and connections are an integral part of people's support systems. The relationship between social integration and health is well established.⁴³ When people face barriers in connecting with members of their social networks, they can become isolated and lonely.

The right of disabled people to take part on an equal basis as others in cultural life, in recreational, leisure and sporting activities, and to utilise and develop their own creative, artistic and intellectual potential is protected under Article 30 of the UNCRPD.

Recreation and leisure activities add meaning to life and help to maintain a sense of identity and autonomy. Cultural clubs and informal gatherings foster and maintain cultural and linguistic identity. Opportunities for relaxation, self-expression and learning can result from engagement in recreation and leisure activities. Many are social in that they involve clubs or organisations which bring together people with shared interests or are enjoyed within informal groups of friends and family.

There is growing awareness of the importance of families, whānau and social relationships (including intimate relationships) to the well-being of disabled people in their communities. Families, whānau and social relationships are a major source of 'natural support' for people. There is a need to better understand how families and whānau can be supported in their care of disabled people in the community.

Enduring questions on community and social life

1. Do opportunities for, and methods of, social contact, participation in leisure activities, and participation in community life differ between disabled people and others? If so, how?
2. What barriers and facilitators influence the social contact, participation in leisure activities and participation in community life experienced by disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
3. To what extent do disabled people have control over the social contact, participation in leisure activities participation in community and social life they experience compared with others?
4. Do feelings of belonging and loneliness differ between disabled people and others? If so, how and why?

⁴³ 'A search of the literature published since the mid-1970s ... presented strong evidence that social integration leads to reduced mortality risks, and to a better state of mental health.'

<http://www.sciencedirect.com/science/article/pii/S1047279796000956>

Topic 9: Civic Engagement and Institutional Trust

Civic engagement⁴⁴ is essential for a healthy democratic society. Specifically, in a diverse society, high levels of civic engagement help to ensure that political structures are representative and allow people to contribute to the well-being of their community. Through participation in civic life members of a society can influence local living conditions and shape their community's future.

At its most basic level, civic engagement is the right to express your political voice through voting in local or national elections. Other activities include communicating with your local member of parliament, participation in lobby groups or protests, engaging in public policy formulation, and standing for a governing body.

Disabled people have distinct characteristics and goals that require representation in the civic sphere. It is important to understand levels of civic engagement by disabled people and determine whether they differ from others.

Civic engagement and institutional trust go hand in hand. If people or communities have low levels of confidence or trust in civil and governing institutions, they are less likely to engage with them. When groups are not represented at levels of influence in society they risk marginalisation.

Enduring questions on civic engagement and institutional trust

1. Do levels of civic engagement differ between disabled people and others? If so, how?
2. What barriers and facilitators influence levels of civic engagement by disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
3. Do levels of trust in institutions differ between disabled people and others? If so, how?
4. What barriers and facilitators influence levels of institutional trust by disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
5. To what extent do disabled people have control over their own levels of civic engagement compared with others?

⁴⁴ Includes voluntary work

Topic 10: Crime and Justice

The extent to which people can access various parts of the justice system must be understood in order to ensure that their rights are being met.

Article 13 of the UNCPRD requires that effective access to justice is ensured, including through the provision of appropriate accommodations, where necessary. All people must be able to fulfil roles as direct or indirect participants in legal proceedings.

The UNCPRD also requires that appropriate training is available for relevant people to facilitate an inclusive justice system.

Enduring questions on crime and justice

1. Do patterns of victimisation and crime differ between disabled people and others? If so, how and why?
2. What barriers and facilitators affect equitable participation by disabled people in the justice system in any role (e.g. victim, witness, suspect, offender, juror, etc.)?
3. To what extent do disabled people have control over their participation in the justice system?
4. How well do current justice services, systems and policies meet the needs of disabled people?

Topic 11: Personal Safety and Civil Protection

The right to freedom and security is fundamental and protected under national and international law. These, and all universal human rights, are to be enjoyed by all people without distinction.⁴⁵

It is difficult to assess the extent to which people are actually at risk of being treated badly, exploited or abused. Measures generally cover people's perceptions of their safety in different locations, at different times and when alone or in company. Anxiety, fear and avoidance behaviour can occur if a person does not feel safe, with clear consequences for personal well-being.

Incidents of degrading treatment, discrimination, bullying, and crime victimisation can be monitored to see whether disabled people are disproportionately affected. Articles 14, 15 and 16 of the UNCRPD outline the obligations of ratifying governments to ensure that this is not the case in their country.

Institutional arrangements for public safety and civil protection are important factors in making us feel safe. Emergency preparedness by responsible agencies must take into account the needs of disabled people as must the members of households in which they live. This includes having an emergency kit and plan at home as well as ensuring that agencies involved in rescue operations or disaster relief are trained and equipped appropriately to assist all people in their community.

Under Article 11, the UNCRPD requires that '...all necessary measures are taken to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.'⁴⁶

Enduring questions on personal safety and civil protection

1. To what extent do disabled people feel safe in their homes and communities and does this differ from the experience of others?
2. To what extent are disabled people subject to behaviour that impinges on their right to personal safety and how does this compare with others?
3. What barriers and facilitators affect levels of personal safety and perceptions of personal safety for disabled people (including, amongst other things, attitudes and awareness, and accessibility)?
4. Do levels of individual, household and community emergency preparedness differ between disabled people and others? If so, how and why?
5. Are public safety and emergency relief agencies able to manage all people in their community?

⁴⁵ United Nations (1948) [The Universal Declaration of Human Rights](#)

⁴⁶ UNCRPD Article 11

Topic 12: Products and Technology

A wide range of products are specifically designed or adapted to help people with impairments perform tasks that would be difficult or impossible without them. These so called 'assistive devices' are only one part of the picture. Mainstream manufactured goods also play an important role in mitigating the effects of impairments and enabling greater independence. Examples include 'labour saving devices' such as dishwashers and food processors. These may be the difference between preparing your own meals and being reliant on someone to do it for you.

Adopting a 'universal design' approach to products, environments, programmes, and services allows them to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design⁴⁷.

Understanding the ways in which people use products and technologies to mitigate the effects of impairments and identifying any barriers to doing this, informs the enduring questions below.

Enduring questions on products and technology

1. What products and technology do disabled people use to carry out and participate in the activities they want to do?
2. What products and technology do disabled people need to carry out and participate in the activities they want to do?
3. What barriers and facilitators affect the availability of products and technology disabled people need to do the things they want to do (including, amongst other things, attitudes and awareness, cost and accessibility)?
4. To what extent do disabled people have control over their use of products and technology?

⁴⁷ UNCRPD Article 2

Topic 13: Accessibility

Accessibility is a fundamental issue and affects all the topics discussed in this document. Its inclusion as a separate topic helps to ensure that we can look across all aspects of people's lives through an accessibility lens.

Disabled people should have access, on an equal basis with others, to the physical environment, transportation, information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and rural areas' (Article 9, UNCRPD).

A non-disabling society is a place where all people have equal opportunity to achieve their goals and aspirations.

Enduring questions on accessibility

1. What are the main accessibility issues faced by disabled people?
2. How well do current standards and guidelines, systems and policies achieve desired levels of access for disabled people?
3. What is the cost of not providing equitable access for disabled people?

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Topic 14: Attitudes and Awareness

The importance of attitudes and awareness in the lives of disabled people cannot be overstated. Negative attitudes towards disabled people have been consistently identified as a barrier to their being able to access the same opportunities as others.⁴⁸ Barriers resulting from attitudes to, and awareness of, disability arise in all aspects of peoples' live.

Social inclusion and exclusion are largely determined by dominant cultural values and perceptions⁴⁹. To change community attitudes towards disability complementary methods are needed, including providing information and extending personal contact.⁵⁰

Of on-going interest and concern is the importance of understanding what it means to self-identify as a disabled person and how this changes over time.

Enduring questions on attitudes and awareness

1. What are the predominant/common attitudes towards disability and disabled people?
2. To what extent are people aware of inequities faced by disabled people?
3. How are people's attitudes towards disability and disabled people being influenced⁵¹?
4. To what extent do disabled people feel discriminated against compared to others?
5. To what extent are disabled people provided with 'reasonable accommodation'?
6. What are the attitudes and understandings of disabled people towards their impairment/disability?

⁴⁸ <http://www.msd.govt.nz/about-msd-and-our-work/newsroom/factsheets/budget/2010/improving-attitudes.html>

⁴⁹ http://www.melbourneinstitute.com/downloads/hilda/Bibliography/Other_Publications/2013/Thompson_etal_community_attitudes_to_disability_op39.pdf

⁵⁰ http://www.unicef.org/protection/World_report_on_disability_eng.pdf

⁵¹ Including government programmes

Topic 15: Personal Autonomy

Autonomy, being able to decide on one's preferences and make decisions about one's own life, is independence that comes from choice and control. In a non-disabling society disabled people are able to make their own choices and decisions. For example, a child may not be able to attend their closest school if it does not reasonably accommodate their needs, or they might have to live in a residential facility far from friends and family, in order to be cared for.

The first general principle of the UNCPRD outlined in Article 3 is 'respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons'.

Enduring questions on personal autonomy

1. To what extent do disabled people have control over their own lives (personal autonomy) and does this differ between disabled people and others?
2. What barriers and facilitators affect personal autonomy across all aspects of life⁵² for disabled people?

⁵² Includes the right to express one's sexuality

Topic 16: Self-assessed Well-being

Self-assessed well-being is the simplest tool to describe the overall quality of a person's life. Well-being is a complex web of interdependent factors including: physical health, emotional and mental health, wealth and income, social relationships, employment and educational skills/status, civic engagement, cultural identity and participation, safety and security, and housing.

Self-assessed well-being has three distinct components. The first is the person's evaluation of their life, often described as satisfaction. The second focuses on the sense of meaning, purpose and worthwhileness in life. The third is an affect measure which focuses on the balance between positive and negative experiences of moods, feelings, and emotions.⁵³ If there is a significant disparity in multiple areas of well-being between disabled people and others, self-assessed well-being could show this in a straightforward manner.

Personal resilience is the ability to adapt to change, adversity, trauma, or significant sources of stress. This can occur when an aspect of one's well-being (mentioned above) is significantly endangered. This could include: loss of income, relationship difficulties, births, deaths, or natural disasters.

Enduring questions on self-assessed well-being

1. Do levels of self-assessed well-being differ between disabled people and others? If so, how?
2. Why do levels of self-assessed well-being differ between disabled people and others?
3. Do levels of personal resilience differ between disabled people and others? If so how?
4. Why do levels of personal resilience differ between disabled people and others?

⁵³OECD (2015.) *How's Life? 2015 In Figures*. Available from: [OECD Measuring well-being. www.oecd.org](http://www.oecd.org)

Appendix: Members of the Disability Data and Evidence

Working Group (28 September 2016)

1. Diane Ramsay (General Manager, Labour Market and Households Unit, Statistics New Zealand), Co-Chair
2. Megan McCoy (Director, Office for Disability Issues), Co-Chair
3. Dr Catherine Brennan (Advisor, Office for Disability Issues)
4. Litia Tapu (Manager, Well-being and Housing Statistics, Statistics New Zealand)
5. Clare Shepherd (Regional Practice and Implementation Manager, Special Education, Ministry of Education)
6. Anne Hawker (Principal Disability Advisor, Ministry of Social Development)
7. Patrick Power (Principal Advisor, Information Management, Ministry of Justice)
8. Christopher Carroll (Senior Policy Analyst, Disability Policy Team, Ministry of Health)
9. Samuel Murray (National Policy Coordinator, CCS Disability Action) representing disability service providers
10. Dr Brigit Mirfin-Veitch (Senior Lecturer, Centre for Postgraduate Nursing, University of Otago/Director, Donald Beasley Institute) representing university researchers
11. Dr Jonathan Godfrey (Senior Lecturer in Statistics, Massey University, Palmerston North) representing Disabled People's Organisations
12. Lance Fowler (Senior Insights Consultant, Analytics and Reporting, ACC)
13. Kevin Eames (Advisor, People and Environment, Ministry of Transport)